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February 26, 2007

Public Hearing In Favor of: Proposed Bill No. 190:

An Act concerning an income tax deduction for expenses associated with organ donation.

Committee Members;

My name is Audrey N. White; I live in West Suffield Ct and am employed as a Kidney Transplant Coordinator at the Hartford Hospital Transplant Program. I am here today to testify on behalf those this Bill would assist. Real people that I know, as their kidney transplant coordinator, those who have been through our transplant program and those vet to come:

<u>SM</u> – 6 months old. His parents, both 25 years old, who trying to make sense out of their child's illness as he starts dialysis and is fed through a G-tube. <u>Parents unable to consider donation due to loss from work/wages and already lost time due to a sick child.</u>

<u>EL</u> – now in first grade. His Mother an at home caretaker unable to work prior to the kidney transplant due to the care necessary for her son - his Father sole family support, donated his kidney. Shortly thereafter, EL required a liver transplant. <u>Devastating to them as a family financially - overall due to medical expenses, prescriptions and lost time form work.</u>

<u>CL</u> – 27-year-old sister of JH who needs a kidney transplant. She is unable to donate as <u>personal finances prohibit</u> her from donating. <u>CL is sole support of herself and 7 y/o son, with only one week of vacation time from her job as a certified nurses aid.</u>

I wish that I were allowed to put the faces of these very real and courageous people before you. I ask you to seriously consider the passage of Bill 190 as these faces and names never completely go away.... they are simply replaced by new



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new names and faces and devastating emotional and financial concerns.

Consider the self employed, who have nothing to fall back on, the construction worker with no benefits to support his/her time off. Should we be considering mandating employers offer paid leave for kidney donors as well as this Bill?? This Bill is at least a step in the right direction.

End Stage Renal Disease (ESRD) is on the rise. It is a Public Health Issue as per the CDC. It is a very important health problem in the US per the NIH and represents a large and growing economic burden to society.

For those of you present today many may be unaware of the staggering health care costs associated with ESRD. In 2001, ESRD costs were 6.4% of the entire Medicare budget, at a staggering \$15.4-\$22 billion.

Please act responsibly on the public behalf. ESRD does not respect age, race or gender. It affects ones' overall health, quality of life and life expectancy. It is in the top 10 causes of death in the US.

Did you know that as a child with kidney disease your growth stops? That you are chronically anemic and so fatigued that trying to work every day is a struggle?

Transplantation extends life expectancy, improves quality of life. A kidney transplant allows one to grow, corrects anemia and so many other health problems associated with ESRD. Are you aware that brothers and sisters and parents of those in need of a kidney are devastated either emotionally, because they cannot help, or financially because they did step forward? (25% of potential kidney donors don't donate due to the financial burden) 5 years ago, our program transplanted over 34 people with living kidney donors. In 2006, we had only 24 living donor transplants. The others without donors?? Waiting on a deceased donor kidney transplant waiting list.

Could this number of living donors change??

Shouldn't it be encouraged to change?

Are we not left with the responsibility to affect this change??

I cannot begin to count the number of people I have met, counseled and assisted at this most vulnerable and personal of times over the last 14 years. These are all very real people to me and I hope I have been able to make them real to you.

Think about it. ESRD could affect someone in your life at anytime and it most likely will, as 1 out of every 9 people in the US will be diagnosed with kidney disease. So take a good look around you.

Please vote in favor of Bill 190.

Respectfully submitted,

Quedecy W. White RN Audrey N. White, RN

Kidney Transplant Coordinator

Hartford Hospital Transplant Program

Board of Directors

National Kidney Foundation of CT

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